

Children and Youth with Special Health Care Needs



2011 Family Survey

Planning for the Future



Our Vision—Healthy Kansans Living in Safe and Sustainable Environments

Children and Youth with Special Health Care Needs 2011 Family Survey

Table of Contents

EXECUTIVE SUMMARY	iii
PROGRAM BACKGROUND	1
STUDY OBJECTIVES.....	1
STUDY METHODOLOGY	1
<i>Survey Population:</i>	1
<i>Statistical Analysis:</i>	1
SURVEY RESULTS	2
<i>Survey Respondents in Comparison to Everyone Seen in Clinics:</i>	2
<i>Characteristics of Survey Takers:</i>	3
<i>Health Information Sources for Child's Health Needs:</i>	4
<i>Patient Care Coordination:</i>	5
<i>Unmet Medical Service Needs</i>	6
<i>Patient Unmet Needs for Doctors/ Primary Care Providers (PCP)</i>	8
<i>Oral Health Needs and Services</i>	9
<i>Children's Health Needs and School:</i>	10
<i>Health Insurance Coverage and Medical Needs Not Covered by Insurance:</i>	11
<i>Family Financial Difficulties</i>	13
<i>Patient Skills/Abilities</i>	14
<i>Requested Services:</i>	15
SURVEY CONCLUSIONS.....	16
APPENDIX 1: 2011 CYSHCN FAMILY SURVEY	18
APPENDIX 2: COMMENTS FROM FAMILIES ABOUT FINANCIAL DIFFICULTIES ..	22
ADDITIONAL RESPONSES RECEIVED ON THE SURVEY	23
<i>General Feedback</i>	23
<i>Transition</i>	23
<i>Clinic Experience</i>	23
<i>Care</i>	24
<i>Insurance</i>	25
<i>Requests</i>	25

EXECUTIVE SUMMARY

Children and Youth with Special Health Care Needs (CYSHCN) is a state and federally funded program. CYSHCN is involved in the planning, development, and promotion of specialty health care for children and youth with disabilities. To meet the needs of patients served by the program and fulfill goals set by stakeholders at the Maternal and Child Health 2015 Needs Assessment, a survey was conducted at clinics sponsored by CYSHCN. Individuals were asked 20 questions about unmet medical needs and services, financial impact, care coordination, and concerns about patient's skills/abilities. Individuals were asked to complete the survey during their specialty clinic appointments between April and July of 2011. Two hundred and thirty-three individuals (overall response rate of 18.5%) answered the 2011 Family Survey. The survey found that:

- Half of respondents reported the patient received some form of care coordination
 - Care coordination was most commonly provided by nurses and social workers
 - Approximately one out of five individuals (19.2% of respondents) used more than one professional to coordinate care for their child/family
- Most individuals (82.2% of respondents) obtained services needed by their children/youth and reported no unmet medical service needs
 - Individuals reported the most difficulty in receiving dental care and health screens
 - Insurance or payment issues were the primary reasons listed for not receiving a medical service
- Majority of individuals (90.6% of respondents) had no difficulty getting routine care for the patient from their doctor
 - Of those who reported difficulties, finding a local doctor that could care for their children's health needs was the most common reason
- Although most individuals (76.3% of respondents) reported having access to dental services, access to these services was more limited to patients with public insurance
- 27.9% of parents with school-aged children reported updating their child's individualized health plan when their child's health needs changed.
- The three most commonly cited concerns of individuals who responded to the survey for their children were
 - obtaining adequate health insurance for their child
 - locating an adult specialist that will accept the health insurance of the child
 - knowing what to do in a medical emergency
- The two most commonly requested care coordination services for individuals who responded to the survey were
 - scheduling preventative dental care appointments
 - assistance in applying for community-based services

The gaps and barriers identified by individuals in this survey will be included in the planning of future CYSHCN efforts and in partner discussions.

PROGRAM BACKGROUND

The Children and Youth with Special Health Care Needs (CYSHCN) program, housed within the Kansas Department of Health and Environment, (KDHE) promotes the functional skills of young persons in Kansas who have or are at an increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally.¹

The program is responsible for the planning, development, and promotion of specialty health care for children and youth with disabilities. The CYSHCN program provides defined diagnostic, treatment, and case management services for medically and financially eligible individuals. Services must be prior approved and provided by a contracted CYSHCN provider.

STUDY OBJECTIVES

- Identify the unmet service needs of individuals in the CYSHCN clinics
- Provide information to assist the CYSHCN program in future program planning
- To meet the goals set by stakeholders in the Maternal and Child Health 2015 Needs Assessment

STUDY METHODOLOGY

The survey was a self-administered questionnaire developed by CYSHCN staff. The KDHE Internal Review Board reviewed the survey to ensure that the survey protected family rights and confidentiality. The survey was provided to individuals attending CYSHCN-sponsored specialty clinic appointments from April 1, 2011 through July 31, 2011. The survey anonymously asked individuals 20 questions about patient demographics, unmet medical needs, impact on patient's household finances, patient's care coordination, and patient's sources for medical information. See Appendix 2 for a copy of the survey's questions. Incentives were offered to survey respondents who wished to be entered in a raffle for a chance to win one of three \$25 dollar gift certificates.

Clinic staff handed participants in CYSHCN sponsored clinics the three-page English version of the survey or four-page Spanish version of the survey. Upon completion of the survey, respondents sealed the survey in an envelope provided by clinic staff. The sealed survey was placed in an onsite lock box. Clinic staff periodically sealed the contents of the lock box in an envelope and hand delivered them to CYSHCN or mailed them to the state CYSHCN office in Topeka.

Survey Population:

The survey population included all patients receiving care at clinics under contract with the CYSHCN program.

Statistical Analysis:

SAS 9.2 was used to conduct a bivariate analysis of the survey results that included all participants. Respondents versus non-respondents characteristics were based on the

¹ McPherson M, Arango P, Fox H, Lauver C, McManus M, Newacheck P, Perrin J, Shonkoff J, Strickland B. A new definition of children with special health care needs. *Pediatrics*, 102(1):137–140, 1998.

CYSHCN program data for the patients first visit to a CYSHCN sponsored clinic between April and July.

SURVEY RESULTS

Survey Respondents in Comparison to Everyone Seen in Clinics:

The 2011 Family Survey had a better survey response rate in comparison to the 2009 Family Survey. However, 2011 had fewer Hispanic respondents and represented fewer clinic specialties. Of the 1,258 individuals seen at clinics sponsored by CYSHCN between April and July 2011, 233 (an overall response rate of 18.5%) responded to the 2011 Family Survey. This response rate was slightly better than the 17.0% response rate obtained in 2009. Similar to the 2009 Family Survey, the 2011 response rate was higher for Wichita clinics than the Kansas City clinics (Table 1). Fewer Hispanics answered the 2011 Family Survey (n=54) than the 2009 Family Survey (n=92). Fewer African-Americans (n=21) answered the 2011 Family Survey than the 2009 Family Survey (n=35). No other notable disparities by race and ethnicity were observed. Over 41% of 2011 survey respondents (n=96) did not identify the clinic they attended compared to 10% of respondents (n=22) in the 2009 Family Survey.

Of the 1,258 patients seen in clinic, patients in their early teens aged 11-14 years or patients who had private insurance were not as well represented in the Family Survey as other age groups (Table 1). Over half of the patients seen in the spinal cord, or spina bifida clinics responded to the survey. For individuals seen in clinic who chose to disclose their type of health insurance, the response rate was higher among patients who had only public insurance or patients who had both public and private insurance compared to patients who only had private insurance.

Table 1: Selected demographics of respondents compared to all individuals seen in clinic

Characteristic	Number of Respondents	Number Seen In Clinic	Response Rate (%)
Total	233	1,258	18.5
Area			
Kansas City	55	778	7.1
Wichita	178	480	37.1
Clinic Type			
Cardiology	4	396	1.0
Cerebral Palsy	47	121	38.8
Cleft Lip/Palate	13	60	21.7
Cystic Fibrosis	36	126	28.6
Orthopedic	2	93	2.2
Seating/ Wheelchair	8	120	6.7
Spasticity/ mobility	3	16	18.8
Spina Bifida	7	14	50.0
Spinal Cord	11	20	55.0
Urology	6	20	30.0
Missing	96		N/A*
Other		272	N/A
Age Group			
0-5	76	348	21.8
6-10	58	269	21.6
11-14	22	202	10.9
15-21	48	242	19.8
22 or >	16	48	33.3
Missing/unknown	6	149	N/A
Insurance Type			
Only Private	56	435	12.9
Only Public	118	491	24.0
Private and Public	27	73	37.0
No Insurance	8	36	22.2
Missing/unknown	24	223	N/A

Note: * N/A Not Applicable

Characteristics of Survey Takers:

Of the 233 individuals who answered the survey, 55 (23.6%) individuals were served by Kansas City clinics and 178 (76.4%) individuals were served by Wichita clinics. About half of individuals who answered the survey had children less than 10 years of age (Figure 1). More than four out of five individuals who answered the survey were White (Figure 2). Fifty-four individuals (23.2%) identified themselves as Hispanic and 20 individuals (8.5%) used the Spanish version of the survey. Approximately two out of three individuals who answered the survey had some form of coverage through public health insurance (Figure 3). Two out of five people who answered the survey did not identify a specialty clinic (Figure 4).

Figure 1: Age group of individuals who answered the survey

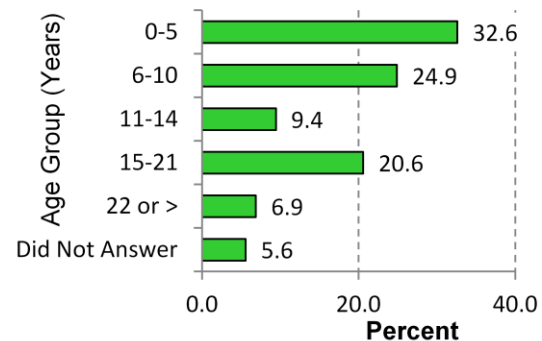


Figure 2: Race of individuals who answered the survey

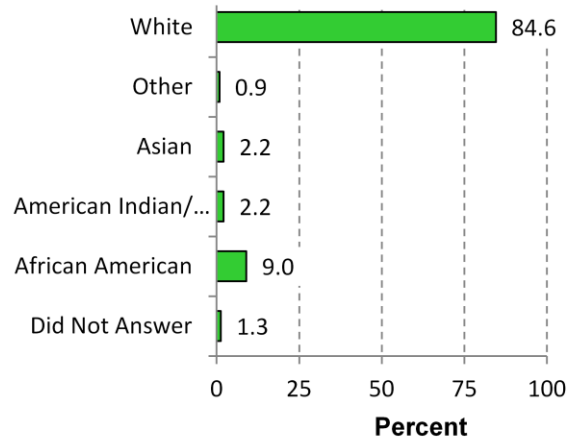


Figure 4: Clinic speciality type of individuals who answered the survey

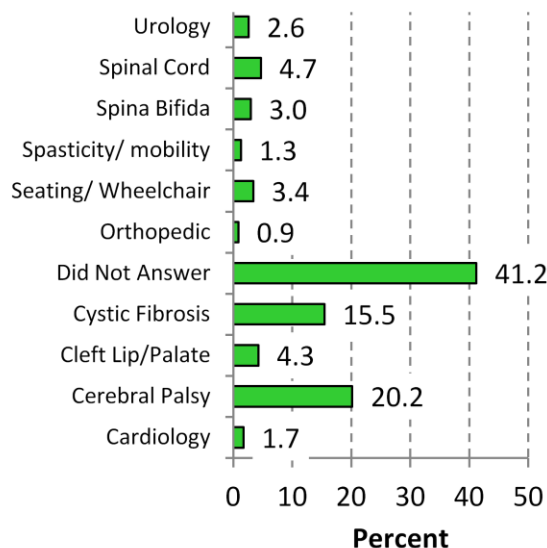
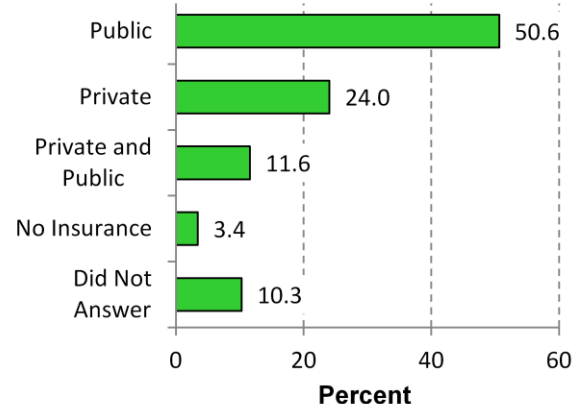


Figure 3: Insurance type of individuals who answered the survey



Health Information Sources for Child's Health Needs:

Individuals served by CYSHCN obtain information from multiple sources to care for their children's health needs. Information sources include the health care provider, internet, social worker, etc. Over half of individuals (n=125, 53.6%) reported using more than one source to look for information and resources to manage their children's health needs (Figure 5). Individuals with only public insurance used slightly more information resources (on average 2.1 different sources of information) than individuals with only private insurance (on average 1.8 different sources of information). Of the individuals who answered the survey and reported the source of their health information, about half reported their doctor as a primary source of information, and two out of five use the internet to help manage their child's health needs (Figure 6). Of the nine individuals who listed other information sources, seven used their child's school, one used their child's therapist, and one individual listed their parents. Of those who listed a single source for health information (n=83), one out of four use only their doctor (Figure 7).

Figure 5: Number of health resources respondents use to manage their child's health care needs

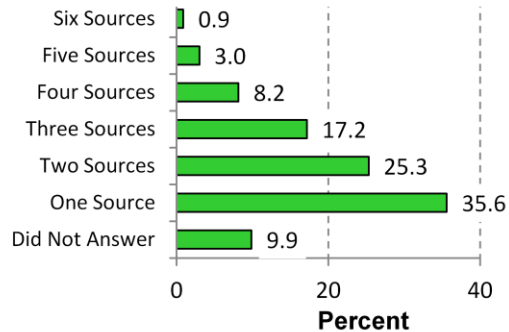


Figure 6: Types of health information/resources used by respondents to manage their child's health needs

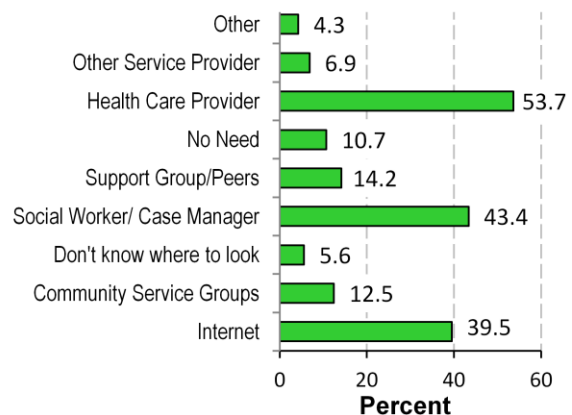
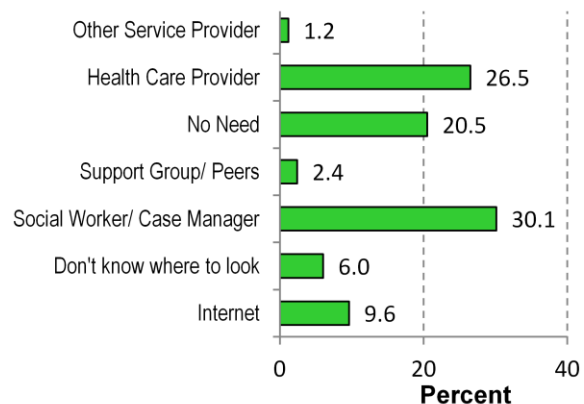


Figure 7: Respondents that use a single health resource (n=83) to manage their child's health care needs by resource



Patient Care Coordination:

Of those individuals who responded, approximately half reported having a single individual coordinating their child's care among different providers or services (Figure 8). The two most common professions listed by individuals for care coordinators were nurses and social workers (Figure 9). For the fourteen individuals who listed other individuals for care coordination, the care coordinators were:

- schools (three individuals)
- doctors (three individuals)
- family members (two individuals)
- clinics (two individuals)
- dieticians/nutritionist s(two individuals)
- brace maker (one family)
- CYSHCN program (one family)

A higher percentage of individuals with only public insurance (n=72, 61.3%) indicated that they had at least one person coordinating care among different providers compared to individuals with only public insurance (n=22, 39.6%). Of those individuals who listed a single care coordinator (n=64), nurses most commonly provided care coordination followed by social workers and case managers (Figure 10).

Figure 8: Number of professionals coordinating care for respondents with children (n=204)

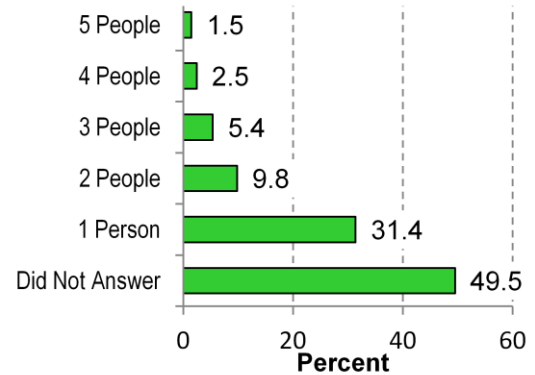


Figure 9: Type of professionals coordinating care among different providers or services for individuals

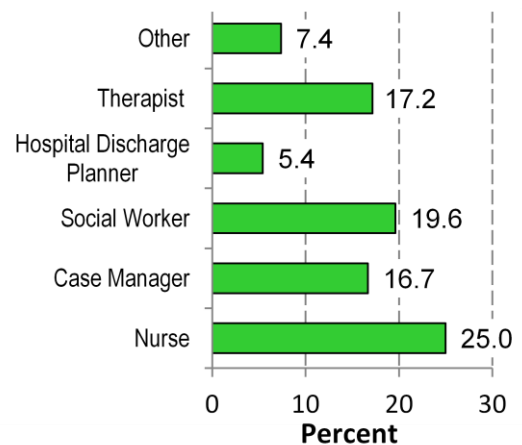
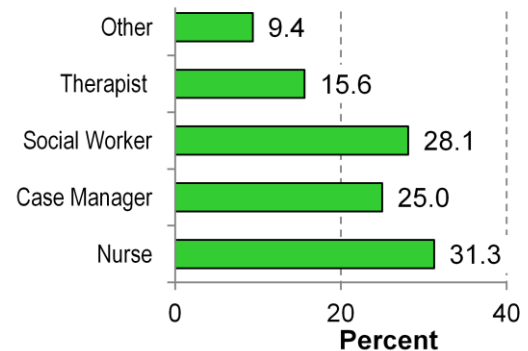


Figure 10: Respondents with a single person coordinating care (n=64) by type of professional



Unmet Medical Service Needs

Four out of five individuals (80.2%) who answered the survey were able to get the health services needed by their child(ren). Of the individuals who answered the survey (n=233), more individuals reported problems obtaining dental care, health screenings and vision/hearing care for patients (Figure 11). In each of the eleven health services polled, the most commonly cited reason for patients not receiving needed health service were insurance or payment issues.

The two most common reasons cited for patients not receiving needed dental care were insurance or payment issues and problems with their doctors (Figure 12). Patients who did not receive needed dental care (n=29) were more likely to be of teenage age (n=13, 18.4%) than children under ten years old (n=8, 6.2%). Patients that had a social worker/case manager (n=9, 23.4%) help coordinate their care were more likely to report difficulties in obtaining needed dental care than patients getting care coordination from other professionals (n=20, 9.5%).

The most commonly cited reason cited for patients not receiving needed health screenings was insurance or payment issues (Figure 13). Patients who did not receive needed health screenings (n=22) were more likely to: have only public insurance (n=10, 8.9%) than only private insurance (n=2, 3.6%); were of teenage age (n=14, 14.2%) than being children under ten years old (n=7, 7.4%); or receive care coordination through a social worker/case manager (n=8, 21.3%) than from other professionals (n=14, 6.8%).

Figure 11: Type of health service not received within the last 12 months

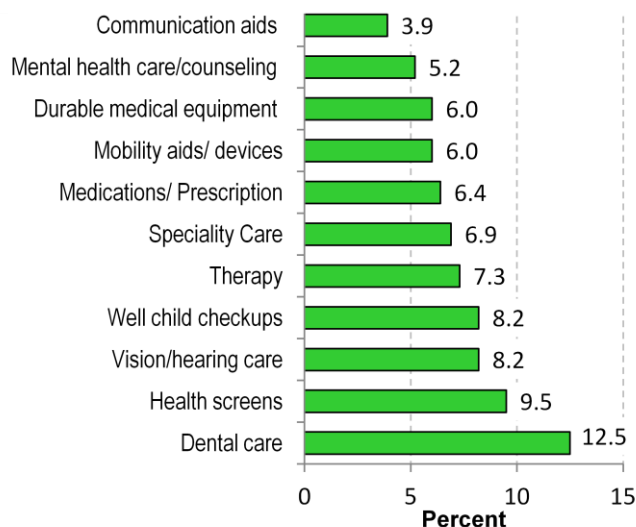


Figure 12: Percent of patients (n=233) who did not receive needed dental care within the last 12 months by reason

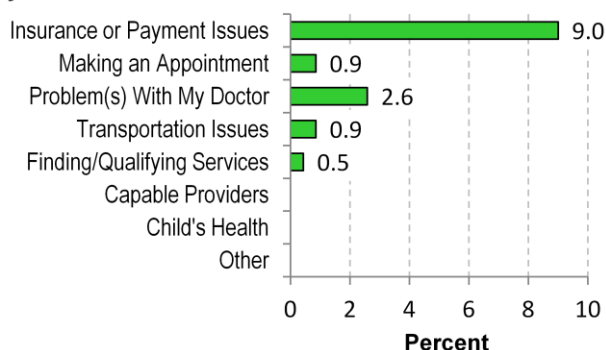
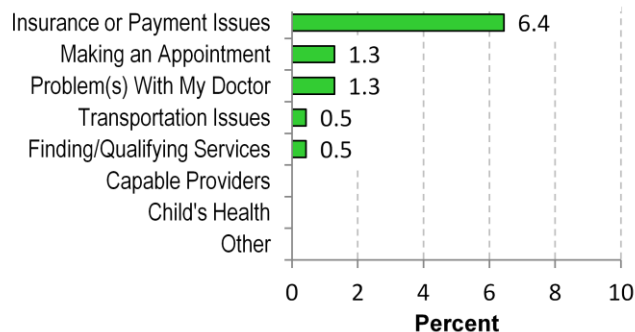


Figure 13: Percent of patients (n=233) who did not receive needed health screenings within the last 12 months by reason



The most commonly cited reason for patients not receiving needed vision/hearing care was insurance or payment issues (Figure 14). Patients who did not receive needed vision/hearing care (n=19) were more likely to have only public insurance (n=9, 8.4%) than only private insurance (n=2, 3.6%); were of teenage age (n=8, 11.4%) than being children less than 10-years-old (n=6, 6.4%); or receive care coordination through a social worker/case manager (n=6, 15.4%) than care coordination from other professionals (n=13, 7.2%).

The most commonly cited reason by individuals for patients not receiving well child checkups was insurance (Figure 15). Patients who did not receive well child checkups (n=19) were more likely to have only public insurance (n=9, 8.4%) than only private insurance (n=2, 3.6%).

The most commonly cited reason for patients not receiving needed specialty care was insurance or payment issues (Figure 16). Patients who did not receive needed specialty care (n=16) were more likely to have only public insurance (n=8, 7.5%) than only private insurance (n=2, 3.6%); or were of teenage age (children (n=8, 11.4%) than children under 10 (n=6, 4.9%).

The most commonly cited reason for patients not receiving needed medications/prescriptions was insurance (Figure 17). Patients who have only public insurance (n=8, 7.5%) were more likely to report not receiving needed medications/prescriptions than individuals with only private insurance (n=1, 1.7%).

Patients who did not receive needed mobility aids/devices (n=14) were more likely to report receiving care coordination through social worker/case manager (n=6, 15.4%) than care coordination through other professionals (n=8, 4.1%).

Patients who had a social worker/case manager (n=7, 17.9%) help coordinate their care were more likely to report not receiving needed durable medical equipment than patients getting care coordination from other professionals (n=7, 3.8%).

Figure 14: Percent of patients (n=233) who did not receive needed vision/hearing care within the last 12 months by reason

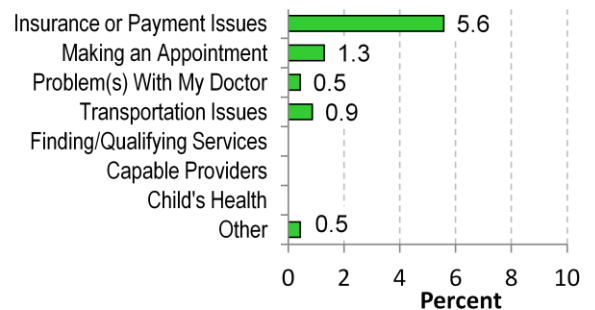


Figure 15: Percent of individuals (n=233) who did not receive needed well child check ups within the last 12 months by reason

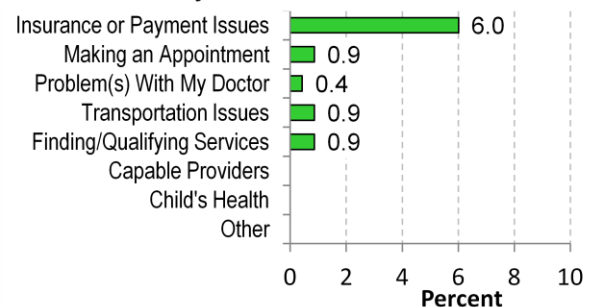


Figure 16: Percent of patients (n=233) who did not receive needed specialty care within the last 12 months by reason

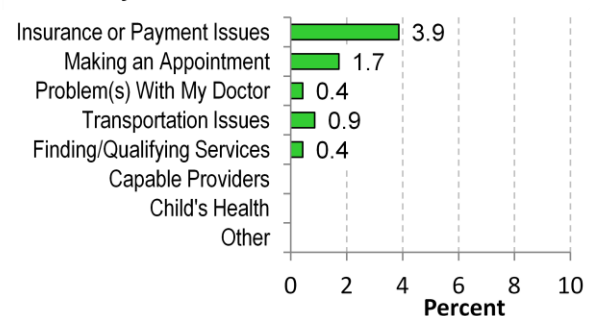
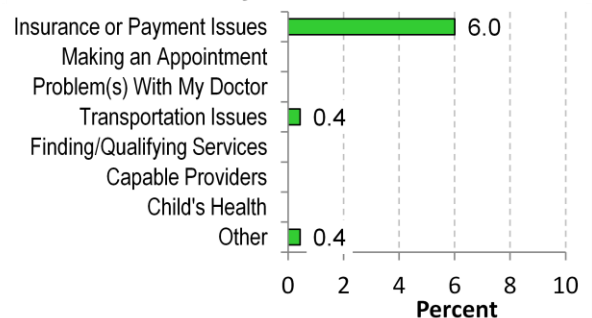


Figure 17: Percent of patients (n=233) who did not receive needed medications/prescriptions within the last 12 months by reason



Patient Unmet Needs for Doctors/ Primary Care Providers (PCP)

The majority of individuals were able to get routine care for their children from their primary care physician (PCP). Less than 10% (n=23) of individuals who answered the survey indicated that they had a problem in obtaining routine care for their child(ren). The two most commonly cited reason for patients not obtaining routine care was the inability to find local doctor could care for child's needs and insurance or payment issues (Figure 18). Of the five individuals that indicated other reasons; three listed specific reason—one responded that different providers provide different services; one had difficulty making appointments for a stomach specialist, and one responded that no PCP wants to treat regular problems unless they could link it to cystic fibrosis.

Patients that reported problems with their PCP were more likely to have only public insurance (n=11, 10.2%) than only private insurance (n=2, 3.6%); be 15-21 years of age (n=11, 17.2%); or receive care coordination from a social worker/case manager (n=12, 16.7%) than from other professionals (n=10, 6.2%).

Two out of three individuals (n=154, 66.1%) who answered the survey reported that their doctors talked with them about how the patients' health conditions would affect the daily activities of patients. Doctors with patients less than 6 years were less likely to talk about how the patient's health condition would affect the daily activities of the patient (Figure 19).

Figure 18: Reason given by respondents for patients, aged 0-22, (n=210) not receiving routine care

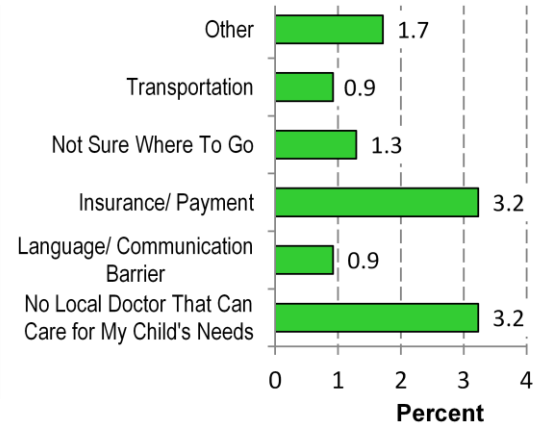
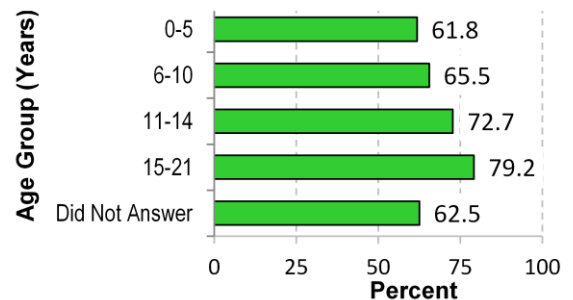


Figure 19: Doctor discuss how the patient's health condition will affect their daily activities by age group



Oral Health Needs and Services

Approximately one out of two school aged children (n=114) —ages 5 through 17— received a dental screening at their school (Figure 20). Approximately one out of four children received restorative dental services (such as fillings, extraction, or root canals) in the past 12 months. Children from the Kansas City clinics (n=20, 37.3%) were more likely to report that they did not receive a dental screen at their school than children from the Wichita area clinics (n=51, 28.8%). For children aged 1-17 (n=172), two out of three received preventive dental care like exams, cleanings, and x-rays.

Children were more likely to get preventive dental services if they were aged 6-14 (Figure 21), or have only private insurance (73.3%) compared to children with only public insurance (50.9%). Three out of four children had access to dental services in the community. A higher percentage of parents with only private insurance (n=48, 88.9%) reported that their child had access to dental care compared to children with only public insurance (n=85, 71.6%). Parents were more likely to report their child had access to dental care if their child was less than ten years (Figure 22).

Figure 20: Type of oral health service received by children

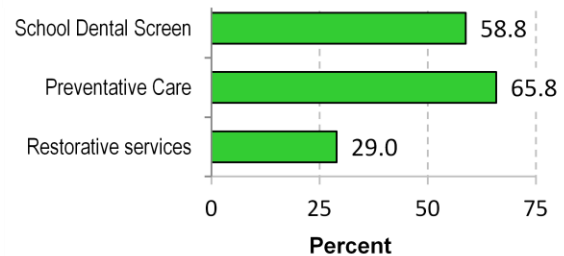


Figure 21: Percent of children aged 1-17 who received preventive dental care by age group

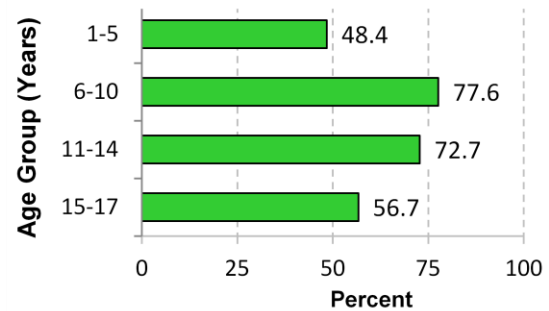
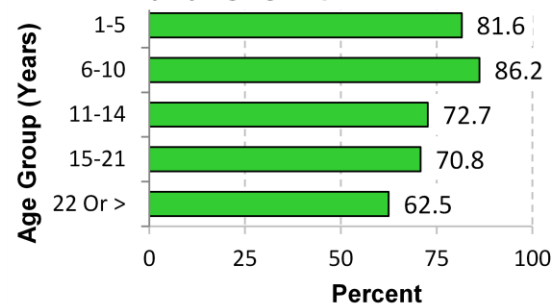


Figure 22: Percent of patients who have access to dental care in the local community by age group



Children's Health Needs and School:

Eight out of ten individuals who answered the survey and had children aged 5-18 years reported that either their children's health needs are addressed at school or they do not need to be addressed at their child's school or in their child's work goals (Figure 23). Slightly more individuals from the Kansas City clinics (8.7%) than the Wichita clinics (3.2%) reported that their children's health care needs were not addressed in their school or work goals. Nearly all individuals whose children's health care needs were not addressed in school or work plans had children aged 5-10-yearsold. Virtually all parents who listed their health care provider as a common source for health information (n=48) had their children's health needs addressed in the child's school or work goals.

Approximately three out of four individuals with school aged children reported their child having an Individualized Health Plan (IHP) developed by a school nurse with input from the student, family and other health care providers. The most common use of IHPs by a parent was discussing the child's educational goals with school staff (Figure 24). One out of seven parents reported that their child's IHP is used every time they see their child's PCP. Over half of children who had an IHP in the school setting (n=17) update the plan when their health needs change (Figure 25).

Figure 23: Children aged 5-18 (n=123) whose health needs are addressed in their school or work goals

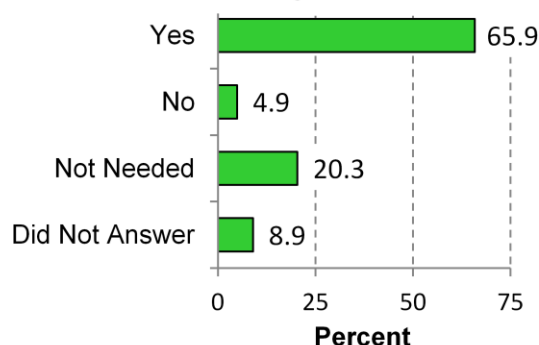


Figure 24: How Individualized Health Plan (IHP) are being used by children aged 5-18 (n=112)

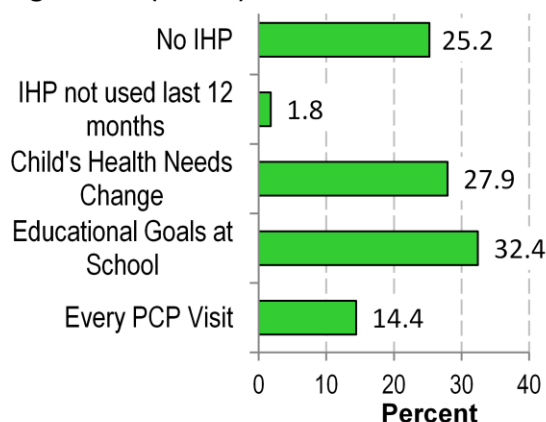
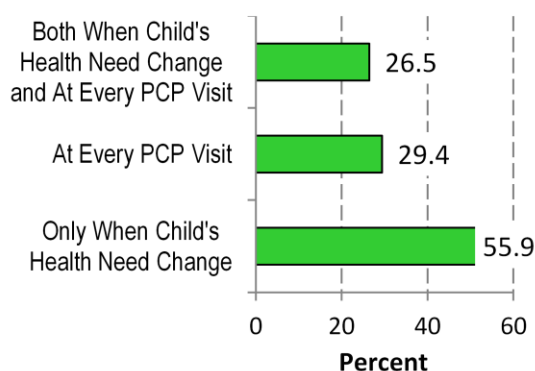


Figure 25: Children, aged 5-18, who use IHP to help plan their educational goals (n=34) by other uses



Health Insurance Coverage and Medical Needs Not Covered by Insurance:

Approximately three out of four individuals who answered the survey indicated that they had health insurance that covered most of the patient's medical costs (or contractually allowable) (Figure 26). The percentage of patients who had an unmet medical service need increased when individuals had to cover more of the patient's medical costs out of pocket (Figure 27). Nearly nine out of ten individuals with no health insurance have at least one unmet medical service need. Individuals who reported that the family's insurance covered at least 75% of the patients' medical costs were more likely to have only public insurance (n=103, 87.3%) than individuals who have only private insurance (n=30, 53.5%). Individuals whose health insurance covered at least 75% of the patients' medical costs were less likely to report issues obtaining routine care for the patient from their PCP (n=10, 5.9%) than individuals whose insurance covered less than 75% of patients' medical costs (n=8, 14.3%). Furthermore, individuals whose health insurance covered at least 75% of the patients' medical costs were also less likely to report that the patient had an unmet service need for medical specialty care (n=6, 3.8%) than individuals whose insurance covered less than 75% of medical costs (n=9, 15.4%).

Figure 26: Percent of patient's medical costs covered by health insurance

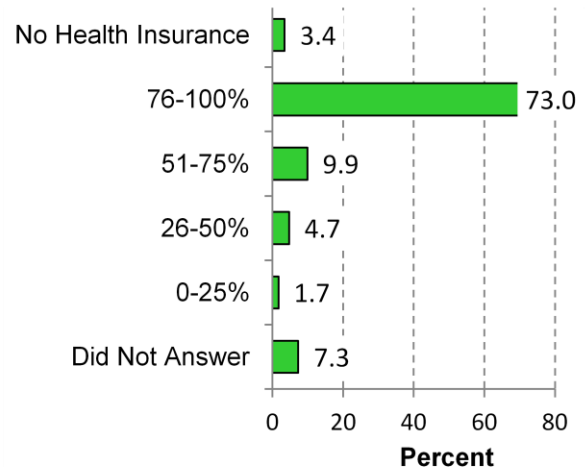
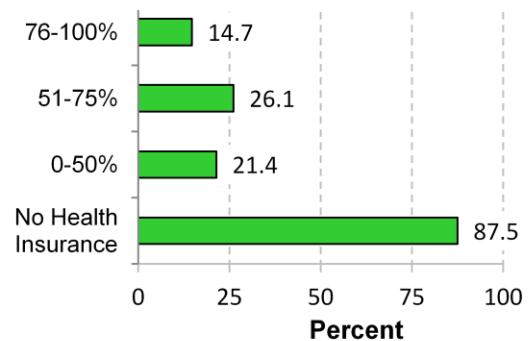


Figure 27: Patients with an unmet medical service needs by medical costs covered by patients' health insurance



About two out of three (n=161, 69.1%) individuals who answered the survey reported that their health insurance covered the patient's medical services. The most common services not covered by health insurance were dental and special dietary products (Figure 28). Three individuals listed other services—geneticist, Botox injections, and vision therapy—that were not covered by insurance. Fewer patients with public insurance reported insurance coverage issues for therapy, medications, diagnostic testing, and dental health services than patients with private insurance (Figure 29). A greater percentage of patients served by the Kansas City clinics (7.4%) reported that health insurance did not cover mental health services than patients served by the Wichita clinics (2.3%). A higher percentage of individuals receiving services from the Kansas City clinics were reported that dental health services were not covered by their family's health insurance (n=11, 20.7%) than individuals served by the Wichita clinics (n=19, 11.4%).

Figure 28: Type of health service not covered for insured patients (n=225)

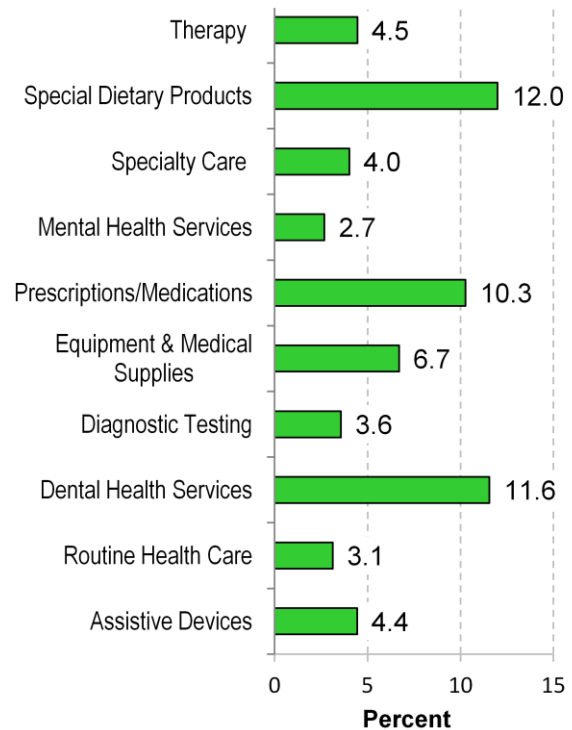
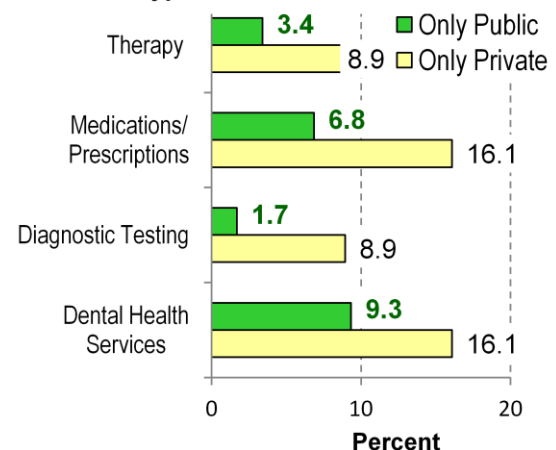


Figure 29: Type of health service not covered for insured patients (n=174) by insurance type



Family Financial Difficulties

About two out of three (n=153, 65.6%) respondents did not indicate that their family experienced a financial difficulty in the past year because of their child's health condition. Of the individuals who did report financial difficulty in the past year, the most commonly reported financial difficulties by individuals were: loss of job or reduction of work hours because of their child's health and paying for health care (Figure 30). Individuals with teenage and young adult patients aged 10-22 years (n=6, 16.7%) were more likely to report a period of time that the patient was uninsured in the past year than individuals with children less than 10 years of age (n=8, 6.4%). Individuals with only public insurance (n=6, 5.1%) who answered the survey were more likely to report difficulties paying for childcare than individuals with only private insurance (n=1, 1.8%).

Sixty-eight and one tenth percent of patients with any unmet medical service needs had at least one financial difficulty in the family in the past year (n=30). About a third of patients with an unmet medical service need had a family member lose their job or cut back their work hours in the past year because of the patient's health condition (Figure 31).

Figure 30: Type of financial difficulty reported by respondents with children (n=210)

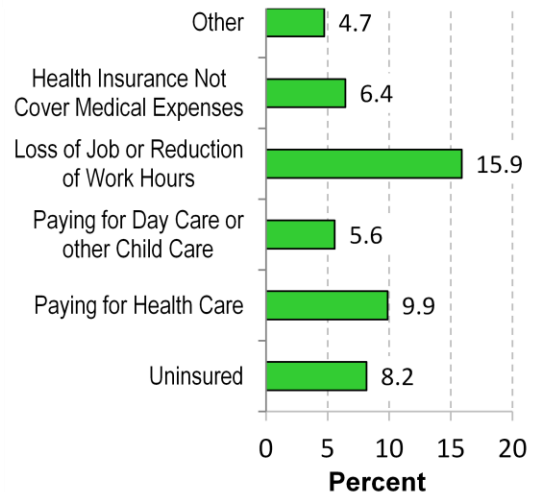
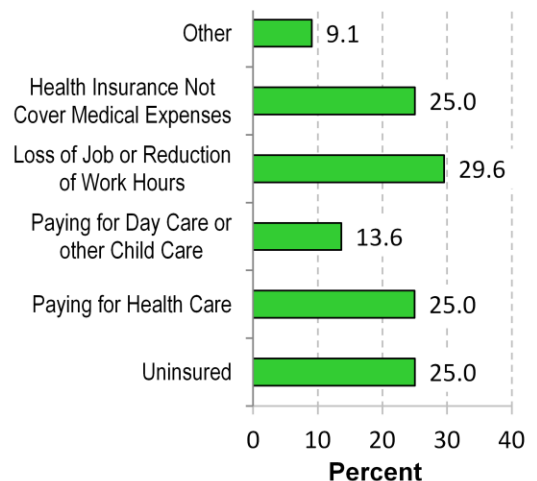


Figure 31: Type of financial difficulty experienced by patients who have an unmet medical service need (n=44)



Patient Skills/Abilities

Individuals were asked about their level of concern for their child in a variety of health care transition activities. Responses are based upon a rating scale of one (no concern at all) to four (very concerned). Individuals who participated in this survey were most concerned about their child's ability to (1) obtain adequate health insurance, (2) locate a specialist that will accept the health insurance of their child as an adult, and (3) know what to do in a medical emergency (Figure 32). Individuals whose child had public insurance gave significantly higher levels of concern for all 10 ability areas than individuals whose child had private insurance. Individuals that had problems obtaining routine care for their child from their PCP (n=23) had lower levels of concern about practicing preventive health and avoiding risky behaviors (2.1 for the average level of concern) than individuals whose child did not have problems obtaining care from their PCP (2.4 for the average level of concern). Individuals that had a child with an unmet medical need (n=46) were slightly more concerned about locating a PCP that would accept their children's adult health insurance (2.6 for the average level of concern) and obtaining adequate health insurance (2.6 for the average level concern) than individuals that had a child that did not have an unmet medical need (2.2 and 2.3, respectively, for the average level of concern).

Figure 32: Percent of respondents who were very concerned about their child's (n=210) ability to...



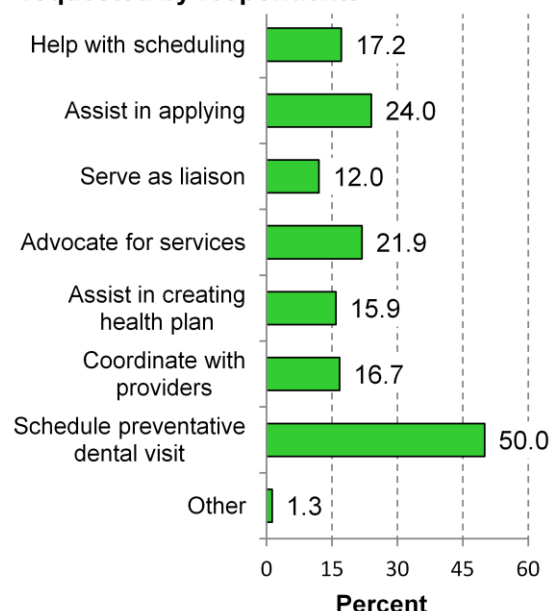
Requested Services:

Three out of five respondents (n=144, 61.8%) requested additional help. The most frequently requested service was scheduling of preventative dental visits, followed by assistance in applying for community-based services (Figure 33). Individuals that had a patient with an unmet medical need or who had difficulties getting routine care for the patient from their PCP were twice as likely to request additional care coordination services than individuals that had a patient who did not report an unmet medical need or who did not have problems getting routine care for the patient from their PCP.

Individuals with only public insurance were more likely to request help with scheduling appointments (20.3% versus 5.1% for only private), advocating for needed health services (17.9% versus 8.2% for only private), or scheduling preventative dental visits (63.3% versus 14.8% for only private) than individuals with private insurance.

Racial minorities and Hispanics (n=22, 79.8%) were significantly more likely to request help in scheduling preventative dental visits than non-Hispanic Whites (n=73, 44.8%). Individuals who had a patient receive care coordination through a social worker/case manager (n=25, 77.6%) were also more likely to request help scheduling preventative dental visits than individuals who had a patient receive care coordination from other professionals (n=70, 44.4%).

Figure 33: Type of additional help requested by respondents



SURVEY CONCLUSIONS

Most respondents attending clinics sponsored by Children and Youth with Special Health Care Needs (CYSHCN) are receiving the needed care and services to help manage their children's health care needs. Ninety percent of respondents did not indicate any difficulties in getting routine care for their child from their doctor. When problems for getting routine care did arise, the most commonly reported issues were finding local physicians to care for their children's health needs and problems with insurance or payment. Eighty-two percent of respondents are receiving the needed services to help manage their children's health needs. When respondents do report an unmet medical service need for the patient, insurance or payment problems are the most commonly cited reason for not receiving the needed medical service.

Respondents attending clinics sponsored by CYSHCN appear to be informed about their children's health needs. Sixty-six percent of respondents reported that their doctors' talk with them about how their children's health needs will affect their daily activities. Most respondents report that for their school-aged children, these health issues are addressed in their children's' educational or work goals. Individualized health plans (IHP) are important documents that recognize a child's health needs in the school setting and may potentially allow school staff to address these health needs at the child's school. The most common use of an IHP reported in this survey was assisting in the planning of the child's educational goals at school. However, less than half of respondents who had school age children and used an IHP at school updated this document when their child's health needs change.

Dental care appears to be a concern for many respondents served by CYSHCN clinics. Seventy percent of respondents with children under the age of 18 reported receiving either a dental screen at school or some form of preventative dental care. One quarter of respondents reported that their children have received some form of restorative dental work. Although most respondents with children reported access to dental services in the community, the ability to access these services was significantly less for children with public health insurance. This difference in insurance access may explain the higher percentage of patients that did not obtain needed dental care because of insurance/payment issues. Difficulties in getting care may also partially explain why half of the respondents would like help in scheduling preventative dental visits for patients at clinics sponsored by CYSHCN.

Respondents are using a variety of resources to coordinate and manage their children's health care needs. Over half of respondents said that they used more than one information source to help manage their child's health needs. The most common sources of health information for respondents were the doctor, the internet, and social worker/case manager. About one out of two respondents reported some form of care coordination for patients. The two most common reported professionals that provide care coordination services to patients were nurses and social workers. Nearly a fifth of respondents receive care coordination from more than one professional.

Although most respondents have health insurance that covers their children's current needs, many respondents are concerned about the insurance for their children's future health needs. Nearly three out of four respondents have insurance that covers at least 75 percent of the patient's medical expenses. One out of ten respondents reported that paying for their child's health care caused financial difficulties for their individuals. Only one out of twenty respondents indicated that their child's health had caused financial difficulties for the family in the past year because the family's health insurance would not cover medical

expenses. Respondents reported the most difficulty in getting insurance to cover specialty dietary products, dental services, and medications/prescriptions. However, about one out of four respondents were very concerned about their children obtaining adequate adult health insurance, locating a specialist that would take their adult health insurance, or locating a doctor that would take their adult health insurance. This concern may be underestimated because individuals with young teenage patients (10-14 years) beginning to make this transition were not well represented in the survey.

About a third of respondents served by CYSHCN clinics have experienced at least one financial difficulty in the past year. The most commonly reported difficulty by respondents was the loss of job or reduction in work hours because of their children's health needs.

The CYSHCN program is dedicated to supporting a system of specialty health care to children with special health care needs and their families in Kansas. The gaps and barriers to appropriate, quality health care services identified through this survey will be included in future program planning.

APPENDIX 1: 2011 CYSHCN FAMILY SURVEY

1. Specialty Clinic _____ 2. Child's/Patient's Age _____

3. Ethnicity ☐ Hispanic ☐ Non-Hispanic

4. Race ☐ African American ☐ American Indian/Alaska Native ☐ White
☐ Asian ☐ Native Hawaiian/Pacific Islander ☐ Other _____

5. Health Insurance ☐ Public (Medicaid, Health Wave, Medicare, etc) ☐ None
☐ Private (Aetna, BCBS, Cigna, Coventry, Humana, TRICARE, etc) ☐ Self-Pay

6. Please indicate the reason why your child **did not** receive any of the following services in the last 12 months. *Check all that apply.* If your child received the service, please leave blank.

Service NOT received	Reason Why Service Was Not Received			
	Insurance or Payment Issues	Problem Getting an Appointment	Transportation Issues	Problem (s) With My Doctor
a. Well Child Check-Ups	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. Specialty Care (cardiology, orthopedics, etc)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. Screenings (vision, hearing, etc)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d. Dental Care	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e. Vision/Hearing Care	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
f. Mental Health Care/Counseling Services	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
g. Prescriptions/Medications	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
h. Therapy (Physical, Occupational, or Speech)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
i. Communication Aids	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
j. Mobility Aids/Devices (wheelchair, walker, etc)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
k. Durable Medical Equipment (suction machine, feeding pump, etc)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Is there another reason that any of these services was not received? If so, please explain. Indicate which service by writing the letter before the reason (ex: D – No provider in my community)				

7. A primary care provider (PCP) is a doctor or other medical person (physician assistant, nurse practitioner, etc) who provides routine and preventive care. If you have had difficulties in getting routine care for your child from his/her PCP, please indicate the reasons here. **Check all that apply.** Leave blank if you have not had any difficulties getting care from your child's PCP.

☐ No Local Doctor That Can Care for My Child's Needs

☐ Insurance/Payment Issues

☐ Language/Communication Barrier

☐ Not Sure Where to Go

☐ My child received all necessary care from his/her PCP

☐ Transportation Issues

☐ Other Reason (please specify) _____

8. Has your child's PCP talked to him/her about how their health condition affects their daily activities? ☐

Yes ☐ No

9. Are your child's health needs addressed in his/her school or work goals?

☐ Yes

☐ No

☐ My child's health does not impact his/her school or work performance

10. An individualized health care plan (IHP) is a written document that describes the necessary health care services needed in the school setting. This is generally developed by the school nurse and should include input from the student, family, and/or other health care team members. Which of the following best describes the use of your child's IHP? **Check all that apply.**

☐ It is used every time my child is seen by their PCP

☐ It is used when I talk with my child's school about his/her educational goals

☐ It is used when my child's health care needs change and the plan is updated

☐ An IHP was created, but has not been used in more than 12 months

☐ My child does not have an IHP

11. What percent of your child's medical expenses does your insurance cover each year?

☐ 76-100%

☐ 51-75%

☐ 26-50%

☐ 0-25%

☐ I do not have health insurance

12. What services, if any, are **not** covered by your child's health insurance?

☐ Routine Health Care

☐ Dental Health Services

☐ Mental Health Services

☐ Prescriptions/Medication

☐ Equipment & Medical Supplies

☐ Assistive Devices

☐ Diagnostic Testing

☐ Therapy (Physical, Occupational, or Speech)

☐ Special Dietary Products

☐ Specialty Care (what kind) _____

13. In the past 12 months, has your family experienced any of the following financial problems in regards to your child's medical expenses? **Check all that apply.**

☐ Unable to pay for child's health care needs (including co-pays and deductibles)

☐ Unable to pay for day care or other child care

☐ Reduced income (loss of job or reduction of hours) due to child's health needs

☐ Lack of health insurance

☐ We have health insurance, but the plan would not cover my child's medical expenses

☐ Other _____

14. Do any of the following individuals from your child's PCP office or specialty clinic help your family to coordinate care among different providers or services? **Check all that apply.**

- ☐ Nurse
 ☐ Social Worker
 ☐ Therapist (speech, physical, occupational)
☐ Case Manager
 ☐ Hospital Discharge Planner
 ☐ Other _____

15. Would your family use any of the following care coordination services? **Check all that apply**

- ☐ Help in scheduling my child's appointments and other clinical tests
☐ Assist my family in applying for community-based services
☐ Serve as a liaison between my PCP and specialty providers
☐ Advocate for the services my child and family needs
☐ Assist my family in creating a health care plan with my child's medical team
☐ Coordinate with my child's providers to ensure their health care plan is followed by all providers
☐ Other _____

16. The following items are things that youth should be able to do as they move into adulthood and independence. Please circle the number that best matches how concerned you are that your child will be able to do these things as an adult. (**1 = Not at all concerned; 2 = Slightly Concerned; 3 = Concerned; 4 = Very Concerned**)

Has the knowledge and skills to manage their health condition in their daily life.	1	2	3	4
Can understand the importance of preventive health & avoiding risky behaviors.	1	2	3	4
Ability to take medications and refill prescriptions independently, report side effects to their health providers and obtain necessary equipment or supplies.	1	2	3	4
Ability to communicate their needs and interact with their health care providers.	1	2	3	4
Know what to do in case of a medical emergency and has an emergency plan.	1	2	3	4
Identify and obtain adequate adult health insurance coverage.	1	2	3	4
Will find doctors or other providers who are knowledgeable about their health needs.	1	2	3	4
Are able to find educational, recreational and vocational programs/services that are able to accommodate their health needs	1	2	3	4
Identify a PCP who accepts their adult health insurance.	1	2	3	4
Identify specialists (including oral & mental health) who accept their adult insurance.	1	2	3	4

17. Where do you typically look for resources and information regarding assistance for your child's health care needs?

- | | | |
|--|--|---|
| <input type="checkbox"/> Internet | <input type="checkbox"/> Social Worker/Case Manager | <input type="checkbox"/> Health Care Provider |
| <input type="checkbox"/> Community Service Organizations | <input type="checkbox"/> Support Group/Peers | <input type="checkbox"/> Other Service Provider |
| <input type="checkbox"/> I don't know where to look | <input type="checkbox"/> I haven't had to look for resources | <input type="checkbox"/> Other _____ |

18. In the past 12 months, has your child:

Yes No Don't Know

- | | | | |
|--|--------------------------|--------------------------|--------------------------|
| A. Received a dental screening at their school | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| B. Seen a dentist for preventative services (cleaning, x-rays, exam) | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| C. Seen a dentist for restorative services (fillings, crown, root canal) | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

19. Do you and your family have access to dental care in your local community? ☐ Yes ☐ No

20. Would you schedule your child for preventative dental services if they were available at our clinic?

- ☐ Yes ☐ No

Do you have any other comments you'd like to make? _____

Thank you for helping us to improve our services.

If you have any questions or concerns regarding this survey,
please contact Heather Moore at 785-296-4747

APPENDIX 2: COMMENTS FROM FAMILIES ABOUT FINANCIAL DIFFICULTIES

Services

2010 PT, OT and Speech very limited coverage
Nursing during morning and afternoon
Wheelchair

Insurance

Premiums are about to cause extreme financial problems
We have insurance, but the coverage is poor...and it is too expensive. They raised our premium 18.7% this year!! We are considering dropping all coverage. It's very scary!!!
Co-pays are financial
Insurance has been very difficult in covering pulmazine
The vest was not covered by hillrom
Health insurance does not cover some medications or supplies needed to care for my child
Medical equipment and some services
Out of pocket expense for feeding supplement (for G tube) 4 cans daily
Will no longer cover medical supplies
There's part that we had to pay a lot so we took a while to get the necessary equipment due to lack of money
State Insurance
We can't get any other help because we do have insurance

Employment

I changed jobs
Loss of husbands job has made it very difficult to pay medical bills and food costs
Used most of my sick leave time for Medical appointments

Other

I have 2 children and single parent
No

ADDITIONAL RESPONSES RECEIVED ON THE SURVEY

General Feedback

I don't feel like I fit the criteria for this survey. I am not a child nor have a child with CF.

Everything is OK

Some of the questions do not pertain to me

No. Questions are complicated

I don't know. I would need to talk with my uncle and husband.

None at all

No

Thank you

Transition

My PCP is helpful. His office and nurses help me a lot. He has a social worker through CDDO. They help coordinate our services and life planning. Her age is a 2 yr old. She won't ever be able to make higher decisions so these questions don't apply.

I have a good network set up for my foster son. He is MR also and I do have concerns for when he is an adult. He will need to have a guardian or live in a group setting.

More info for what a child should do when turning adult. My oldest child with Muscular Dystrophy has no INS and still needs assistance. SS not helpful with info.

Clinic Experience

We don't really care for our Dr, we have found an ENT we like better. We feel our Dr groups our child with everyone else and doesn't take care of his specific needs.

The rude blank stares and judgment from staff isn't necessary. Everyone has a bad day, try not to make it worse.

Not easy to get an appointment w/specialist of stomach

No PCP wants to treat regular problems they always want to link it with CF

We have always had great experiences and help here at the clinic

Thanks for all the care our child gets here.

This clinic is wonderful as you gain knowledge and able to see all your child's physicians @ one visit

PCP won't treat Cystic Fibrosis

We appreciate this clinic very much. Being able to see a variety of specialists at one time is wonderful. Thank You!

I have a wonderful team of nurses, doctors, social workers and people who take care of me. They help with every aspect from insurance help to referrals. They are very helpful, I am lucky to have them.

Thank you for this CP clinic. This works very well.

The clinic is very good and have helped us a lot everytime we have been there.

The Cp clinic is a blessing to have...we've lived here for almost 2yrs. We moved from TX and I would have to drive 3hrs to Ft. Worth to see specialists all @ different times & dates, so seeing every specialist he needs in one visit is a real lifesaver.

Thank You.

I appreciate all the time & effort the doctors, nurses & staff devote to the outreach clinic so that I do not have to travel so far out of my way to provide the medical care my son needs. A HUGE THANK YOU TO ALL INVOLVED!!

I would like to thank the services for helping with my child's needs. I am very grateful and do not have the words to express my gratitude.

Everyone here has been so great and supportive. I feel that everyone is there for you.

The spasticity clinic is very helpful. The collaborative knowledge and assessment improves the ability to meet my son's needs. This is a great service they are providing. Thank You!!

The specialty clinic team is really amazing they are so helpful and informative

Is very good CP clinic is staffed by angels. Better care could not be found.

I like the fact that we can see all of the necessary specialists in one clinic - very convenient for us as we are 5hrs. away

Care

Do not receive any assistance due to undocumented status

She has her dental care

Having to have dentures due to teeth problems

Looking for dentist to handle special needs

My child sees a dentist twice a year and every other year she's had preventive services in hospital

Getting her in hydro therapy in the pool

My child has just turned 21 in May and her teeth has to be cleaned every four months for preventative dental care due to her medication this task is needed

We hope the hospital will continue to provide clinics and care for their children, they do a good job.

We have most of this figured out independently

NEED to get hydrotherapy (PT) -- has medicaid issues and diaper not allowed in school

Insurance

Husband a doctor. we can afford what insurance doesn't cover. I am stay at home mom. We will care for him at home. Needs total care.

My child has seen a doctor in the past 6 months. But prior to that it was almost a year because we did not have medical insurance. We had an application in for healthwave but it took a very long time to get approved. Then the amount of time it took to find a doctor that would accept our insurance was also very lengthy.

Insurance companies still are wanting to charge extra for her past medical procedure & exclude her coverage for it. The premiums for self insuring are costing our family over 60% of our income. We have dropped dental & pay for it out of pocket now.

I would like for my child's insurance to pay for his dental care.

Some of these items my son needed at some point of time he didn't receive because his medical card could or wouldn't pay for some prescriptions and some medical equipment, we had to wait for several months to find out another alternative and wait for medical to maybe qualify

Dentist dropped medicaid. now he has private delta insurance but mom trying to find dentist who will take special needs and will sedate since he has turned 21 created some issues

Requests

Insurance improvements for disabled individuals

Having the clinic available with all the doctors and specialists in one place is extremely helpful and beneficial to the patients and their individuals. Adding a dental service to the clinic would make things even more beneficial. The staff would make things even more beneficial. The staff would be familiar w/the children w/special needs and it should be more comforting for the patients and the dental staff and individuals

My child has ongoing PT needs, 6 months PT thru Medicaid is not adequate Would be nice to have some to transport to and from appointments so I didn't have to miss so much work Would be nice if all medical support team members communicated with each other

I believe the biggest factor for our family was lack of knowledge in wester/central KS. Did not know what needed to be done or where to go! Even the Dr's were not knowledgeable about it in our case. Need to find a great community/family liaison to help find services and their locations. Even better to have someone in bigger cities to help individuals get to services they need, instead of just 'making do' with what they have.

Someone available to educate about services available from hometown to going for services in larger city. Finding education for correct services.

Help getting funds for equipment not covered by my insurance

Therapies and school

